

AHRQ National Webinar on Transforming Healthcare Through Patient-Generated Health Data Integration

Presented by:

Ida Sim, MD, PhD Leslie Lenert, MD, MS

Moderated by:

Chun-Ju (Janey) Hsiao, PhD Agency for Healthcare Research and Quality

Agenda



- Welcome and Introductions
- Presentations
- Q&A Session With Presenters
- Instructions for Obtaining CME Credits

Note: You will be notified by email once the slides and recording are available.

Presenter and Moderator Disclosures





Deborah J. Cohen, PhD
Presenter



Ida Sim, MD, PhD
Presenter



Leslie Lenert, MD, MS
Presenter



Chun-Ju (Janey) Hsiao, PhD Moderator

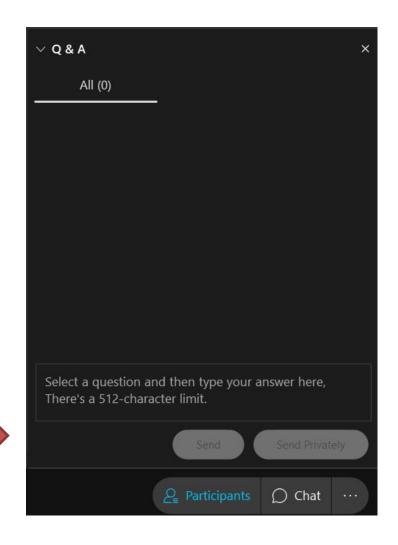
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- Panelist Disclosures: Dr. Cohen, Dr. Sim, and Dr. Lenert have no relevant financial interests to disclose.
- Moderator Disclosures: Dr. Hsiao has no relevant financial interests to disclose.
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- Commercial support was not received for this activity.

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- At any time during the presentation, type your question into the "Q&A" section of your WebEx Q&A panel.
- Please address your questions to "All Panelists" in the drop-down menu.
- Please include the presenter's name or their presentation order number (first, second, or third) with your question.
- Select "Send" to submit your question to the moderator.
- Questions will be read aloud by the moderator.



Learning Objectives



At the conclusion of this webinar, participants should be able to:

- Understand the current state and recommendations of patient-generated health data (PGHD) integration.
- Learn different technical architectures and workflows that support the collection and integration of standardized PGHD, either self-reported by patients or directly from devices.



Integrating Patient-Generated Health Data into EHRs in Ambulatory Settings

Deborah J. Cohen, PhD

Professor, Department of Family Medicine
Oregon Health & Science University School of Medicine

Overview and Learning Objectives



Overview

- Findings and recommendations from an environmental scan related to PGHD integration in ambulatory settings (Led by Duke University's Ryan Shaw and OHSU)
- Identify key areas of development and learning related to PGHD integration (practical guide development (Led by OCHIN's Dave Boston and OHSU)

Learning Objectives

- After participating in this session, the learner should be better able to:
 - Identify the potential impact of integrating PGHD in ambulatory settings
 - Understand the state of the evidence related to PGHD integration

You can find our full report here: https://digital.ahrq.gov/sites/default/files/docs/citation/pghd-environmental-scan.pdf

You can find the PGHD toolkit here: https://digital.ahrq.gov/sites/default/files/docs/citation/pghd-practical-guide.pdf

Methods



- Environmental Scan
 - Peer-reviewed literature
 - Grey literature
 - Vendor survey and interviews
- Practical Guide Development
 - Leveraged input from the scan
 - Engaged stakeholders in informing and reacting to content
 - Tested and refined guide based on user feedback



Findings: Scoping Review



- Identified 36 peer-reviewed papers on integration of PGHD into EHRs across a range of ambulatory settings
- Types of PGHD included biometric data, questionnaires, and health history
- Diabetes was the most common patient condition (27.7%)
- Apple HealthKit was the most common developer format (25%)
- Themes emerged regarding authentication, resources requirements, patient technical support and training, data delivery to the EHR, data management, and preferences for review

Findings: Guides and Resources



Topics covered included:

- How to select and integrate PGHD in ambulatory setting
- Information about Federal-level legislation governing
 - Data privacy
 - Standardization reimbursement and regulation

Findings: Vendor Perspectives



Growing evidence for PGHD-EHR integration is reflected in the vendor feedback

- Vendors are partnering with institutions to leverage PGHD to improve health outcomes and care coordination
- iOS HealthKit is commonly used due to its maturity, which provides data and security standardization
- Few health systems and EHR vendors directly integrate with Google's Android platform
- The use of interoperability standards such as HL7 and FHIR is growing
- Investment, commitment, and understanding of the many variables that influence successful PGHD integration is vital



Recommendations



- 1. Develop a strategy or blueprint
- 2. Identify champions and early adopters
- 3. Tie PGHD to a care delivery model
- 4. Design the workflow
- 5. Use a patient-focused approach with a health equity lens
- 6. Leverage a robust technology architecture
- 7. Create data governance

Recommendations



- 8. Create device guidance
- 9. Provide guidance and education to stakeholders
- 10. Implement and adapt through iteration
- 11. Evaluate against metrics and goals
- 12. Plan for maintenance and scaling
- 13. Provide technical support

Integrating Patient-Generated Health Data into Electronic Health Records in Ambulatory Care Settings: A Practical Guide

Contents of the Guide



Folio 1: Introduction: What is Patient-Generated Health Data and Why is it Important?

Folio 2: Assessing Readiness for PGHD Program Implementation

Folio 3: Assembling a Team to Manage Change

Folio 4: Making the Right PGHD and Information Technology Decisions for Your Practice

Folio 5: Evaluating the Costs of PGHD Implementation

Folio 6: Steps to Successfully Implement a PGHD Program

Practical Guide: 1. Introduction



Key Learning Concepts

- Definition of patient-generated health data (PGHD).
- Integration of PGHD into the electronic health record (EHR) provides clinical decision- making support.
- Benefits of PGHD include increased patient engagement, fuller pictures of health, and more timely interventions.
- The uptick in virtual care adoption provides support for PGHD.
- Efforts to attain health equity should be baked into program planning.
- How to Use This Practical Guide.

Practical Guide: 2. Assessing Readiness



Key Learning Concepts

- PGHD integration may mark a significant change in your practice.
- Incorporate perspectives of staff into PGHD implementation planning.
- Incorporate patient perspectives on PGHD to achieve greater equity and satisfaction.
- Assess your practice and patients for readiness.

Active Learning Exercises

- ACTIVITY 2.1: Organizational Readiness
- ACTIVITY 2.2: Gauge Motivation from Patients and Colleagues
- ACTIVITY 2.3: Roadmap to PGHD Implementation: Key Considerations Relevant to Patient Participation

Potential Solutions to Common Patient Barriers to PGHD Use



		Barriers				
		Lack of Internet access	Low health IT proficiency	Dexterity	Vision	? Language
Solutions	Patient education and instructions		•			•
	Technical support			•		•
	Multiple media		•	•		
	Hello Hola Nĭ hǎo Multiple languages					•
	Community partnerships			•		•
	Wi-Fi hotspots	-				

Practical Guide: 3. Assembling a Team



Key Learning Concepts

- Build the team: Identify stakeholders and find your champions.
- A PGHD Coordinator could be crucial to success.
- External partners are powerful allies.

Active Learning Exercises

- ACTIVITY 3.1: Identify Your Team of Champions
- ACTIVITY 3.2: Assemble a Core PGHD Workgroup

Practical Guide: Tools to Assist with Developing the PGHD Implementation Team



QUALITY REPORTING CHAMPION

- Ensure your practice meets PGHD implementation reporting requirements for regulatory programs, certifications, alternative payment programs (e.g., patient-centered medical home recognition, uniform data system reporting, accountable care organizations).
- Monitor for opportunities to participate in PGHD implementation incentive programs.
- Partner with EHR vendors to automate PGHD-related data capture for reporting purposes.

INFORMATION TECHNOLOGY CHAMPION

- Assess bandwidth and equipment needs in various settings (e.g., exam room, remote office, patient home).
- Consult on technology solutions and equipment vendors.
- Install, configure, test, and maintain PGHD implementation hardware and software.
- Support patients with initial setup/validation/calibration for prescribed remote monitoring devices, fitness trackers/wearables.
- Assist with staff and patient PGHD implementation training and troubleshooting.
- Coordinate with MTT assisting patients in their homes.
- Work with EHR vendor to ensure interoperability for seamless, bidirectional PGHD exchange.

Practical Guide: 4. Making Decisions



Key Learning Concepts

- Identify information technology best suited to your PGHD implementation.
- Legal, compliance, and security factors must be considered ahead of implementation.

Active Learning Exercises

 ACTIVITY 4.1: Roadmap to PGHD Implementation: Key Health IT, Legal, Compliance, and Security Considerations

Practical Guide: How to Select Devices



Selecting Devices for Your PGHD Program: By consulting with your EHR vendor to identify the best device options for your EHR, you will narrow your range of options. You may want to test some sample devices to compare quality, costs, usability, and functionality on different mobile devices, such as iPhone and Android smartphone platforms. Your selection decisions should also be informed by the following considerations.

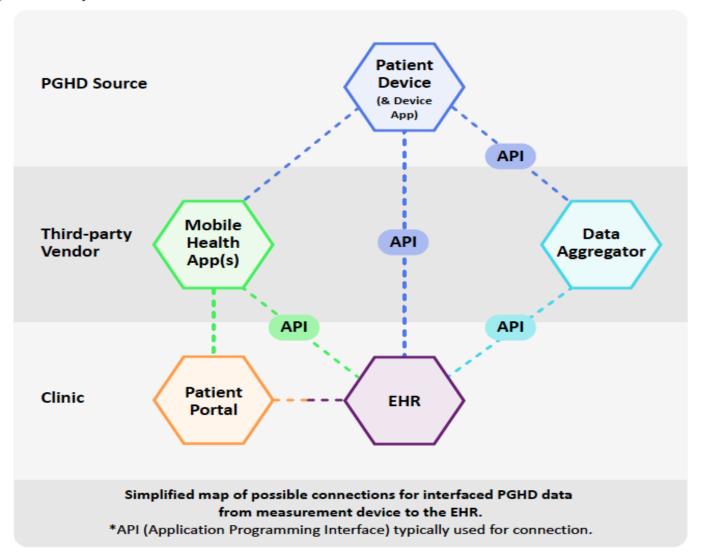
Tip: The good news is that you do not have to do all this research and testing yourself. Some EHR vendors furnish PGHD device kits tailored to specific clinical conditions. There are also third-party vendors who offer PGHD packages and/or facilitate EHR integration. Identifying these available options will significantly lighten your workload.

Pathways to PGHD Integration into the EHR: PGHD integration is often complex and dynamic. Some vendors facilitate the integration of data into the EHR directly, while others may require the use of a third-party aggregator that accepts the PGHD data from devices and prepares the data for upload. Additionally, the patient portal may be utilized for patient identification and other communications.

Simplified Connection Network Between a Device and the EHR



Figure 1. Simplified Connection Network Between a Device and the EHR



Practical Guide: 5. Cost



Key Learning Concepts

- Identify factors that will influence your program's financial sustainability.
- Develop a budget to implement, grow, and sustain your program.
- Estimating initial and ongoing costs.
- Identify sources of funding and cost savings.

Active Learning Exercise

 ACTIVITY 5.1: Roadmap to PGHD Implementation: Key Financial, Reimbursement, and Reporting Considerations

Practical Guide: Return on Investment (ROI)



ROI is a common analysis to gauge value. There are multiple ways to look at the financial ROI for PGHD programs in your practice. The billing and reimbursement champion on your team will be able to provide information about the payer rates of reimbursement for various PGHD related services. These figures can be used to develop projections for future PGHD-revenue streams based on anticipated billing volume.

At present, rates of reimbursement are relatively low and will likely not offset all costs related to your PGHD program. As this changes, consider the indirect cost savings generated by a PGHD program.

Estimating Indirect Cost Savings

If you have access to claims and/or EHR data and an expert data analyst, you may be able to guestimate some indirect cost savings. To do this, you may consider conducting some before and after comparative analyses of patients participating in your PGHD program on such topics as healthcare utilization and costs. Ideas you might investigate include the following:

- Frequency of in-office appointments and canceled appointments.
- Increased patient engagement and retention.
- Better patient self-management and health outcomes.
- Fewer missed appointments.

In addition, systemic cost savings related to PGHD integration may be possible. Work with your payers to determine if there are shared benefits for your practice.

Practical Guide: 6. Implementation



Key Learning Concepts

- Set realistic and measurable goals.
- Effectively engage your target group of patients.
- Develop a workflow to support staff engagement and program design.
- Learn before scaling your PGHD program.
- Conduct rapid-cycle tests of change and applying end-user feedback.

Active Learning Exercises

- Activity 6.1: Bringing It All Together: Your PGHD Implementation
- Activity 6.2: Set SMART Goals
- Activity 6.3: Develop Workflows
- Activity 6.4: Evaluate and Refine
- Activity 6.5: Scale Up and Monitor

Practical Guide: Tools and Activities to Assist With Evaluation



A PGHD SMART Framework: Example

- **S Specific**: Improve BP in 25 patients with uncontrolled hypertension through PGHD.
- M Measurable: Patient BP and BP cuff device usage data are structured and easily retrievable. Survey responses can be summarized, and comments coalesced into prevailing themes.
- A Attainable: Three months is adequate for our clinic to identify patients, disperse devices, and train participants. A subsequent 3 months is adequate to capture and review patient data, schedule followup appointments, assess performance using our metrics, and conduct and assess surveys.
- **R Reasonable**: It is certainly a worthy goal to improve BP in this population and reduce risk of cardiovascular events. This will also provide valuable insight into the use of PGHD in future population health initiatives.
- **T Time-bound**: These are clear and achievable. Six months is a tight cycle, but the program involves only a small group of staff and patients

Collaborators



Duke University

- Ryan J. Shaw, Ph.D., R.N.
- Mina Boazak, M.D.
- Gloria Porter, M.S.N., R.N.
- Jedrek Wosik, M.D.
- Rowena Dolor, M.D., M.H.S.

Oregon Health & Science University

- Deborah Cohen, Ph.D.
- LeAnn Michaels
- Martha Snow, M.P.H.
- Sarah Bumatay

OCHIN

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- Julie Stone, M.P.H.
- Erica Edwards, M.S.
- Angelea Brown, M.P.H.

Technical Expert Panel

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- James McCormack, Ph.D.
- Richelle Koopman, M.D., M.S.
- Steven Kassakian, M.D., M.S.
- Matthew Roman
- James Pantelas

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Toward Individualized Bouquets of PGHD

Ida Sim, MD, PhD

Professor, Department of Medicine, University of California, San Francisco

Learning Objectives



- After participating in this session, the learner should be better able to:
 - Identify key requirements of integrating patient-reported outcomes into clinical care
 - Understand key pain points in collection and governance of PGHD
 - Appreciate benefits of a standards-based public utility approach to patient-generated data

How do our patients *really* feel?



Social Activities

Medication Adherence

Pain

Cognitive Function

Depression

Pain Interference Physical Function

Fatigue

Anxiety

Sleep

Health-related Social Needs

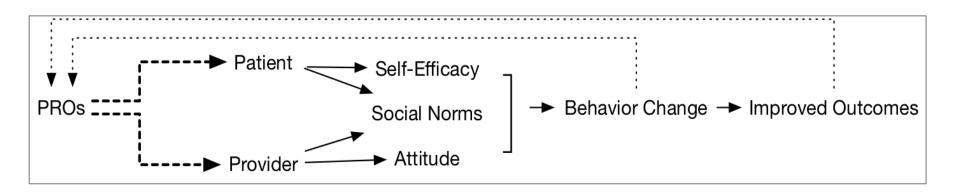
Loneliness

Perceived stress

Underlying Hypothesis



- Patient-reported outcomes (PROs) can improve multiple chronic condition outcomes via two complementary pathways:
 - ► Patient self-monitoring with PROs provides feedback and improves selfefficacy for self-management
 - ▶ PROs inform providers of their patients' heath experience and enable more patient-centered shared decision making

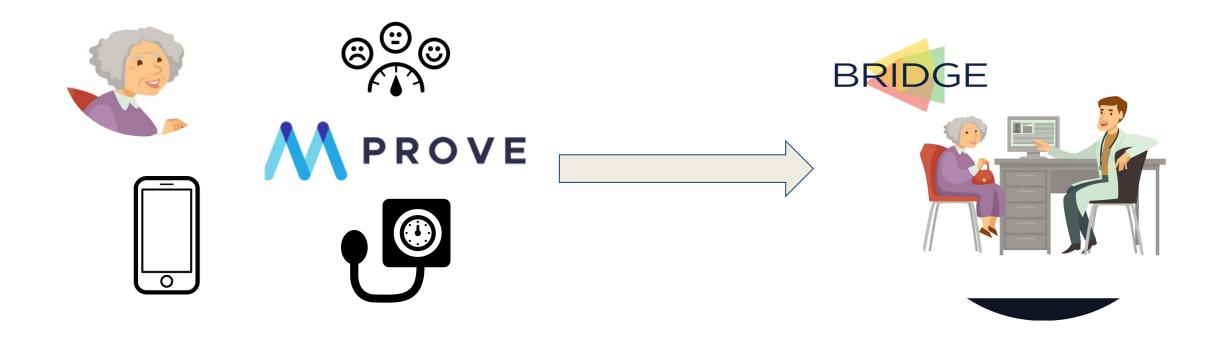


Theory of Planned Behavior

mPROVE Research Project



Enrolling 40 English- and Chinese-speaking patients to track PROs on a smartphone over 6 months. PRO results will be accessible via the BRIDGE dashboard directly within Epic.

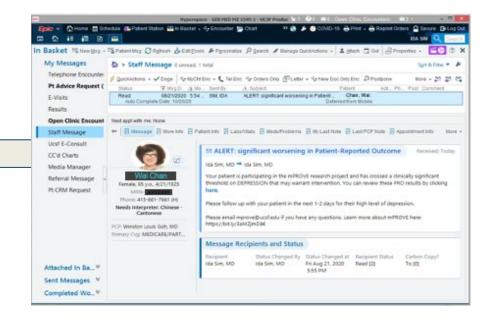


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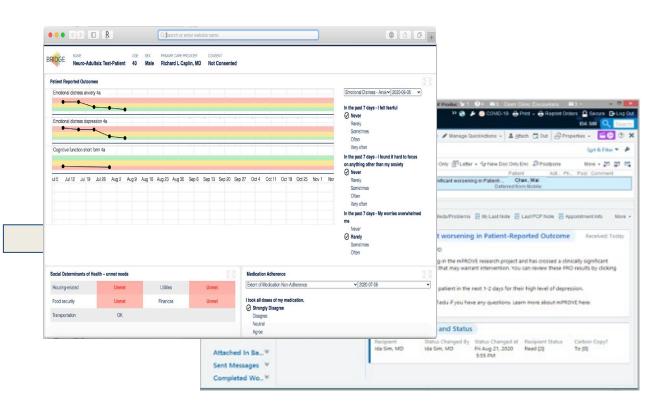


mPROVE Research Project



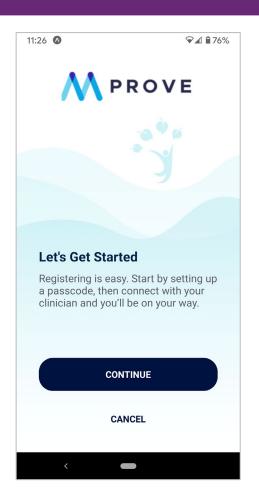
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mPROVE App







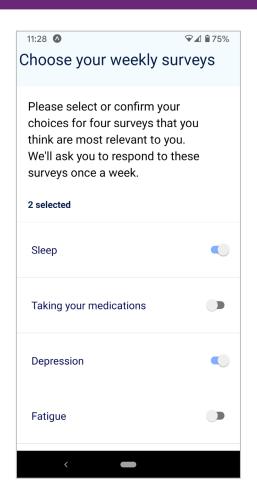


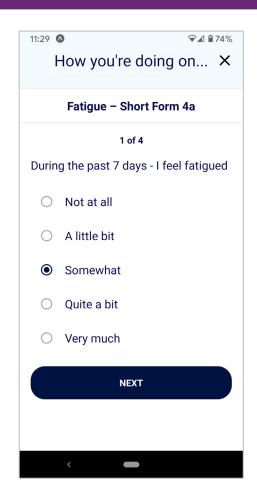


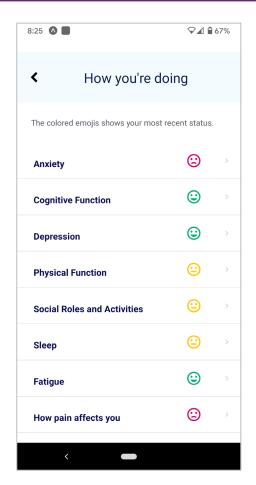
Patients trust UCSF – prominent branding and wording promoting self-efficacy

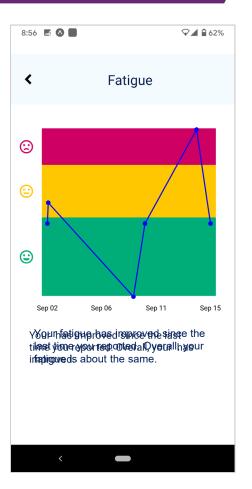
mPROVE App











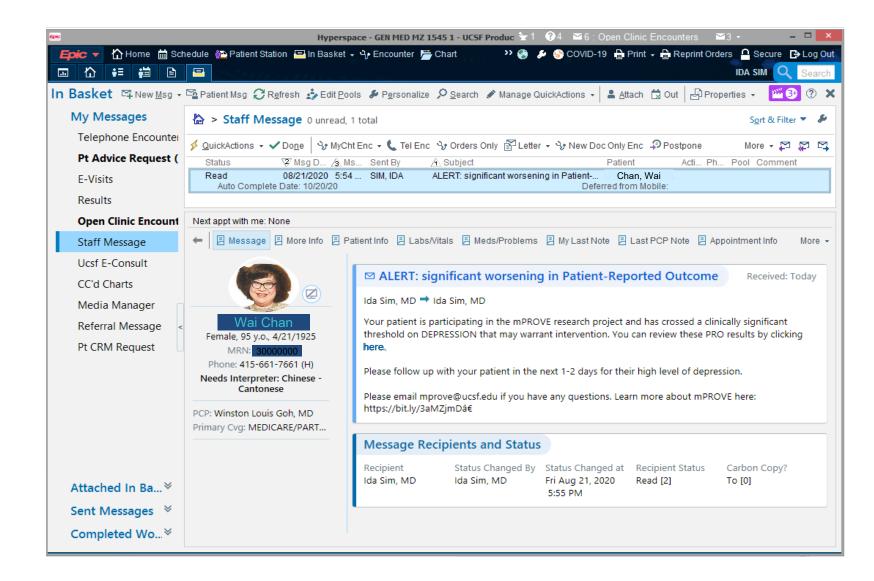
Supporting self-management with PRO tracking

In-Basket: Threshold Warning to PCP



In between clinic visits, if patient PRO exceeds a clinical threshold, PCP gets a staff message.

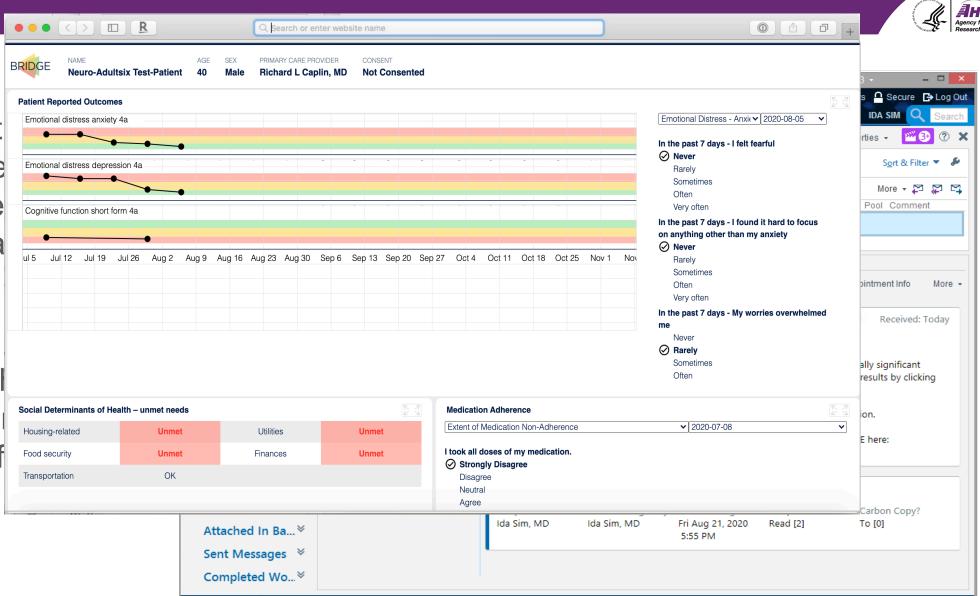
e.g., Ms. Chan's GAD-7 score is 11 (threshold for alert is 10)



In-Basket: Threshold Warning to PCP

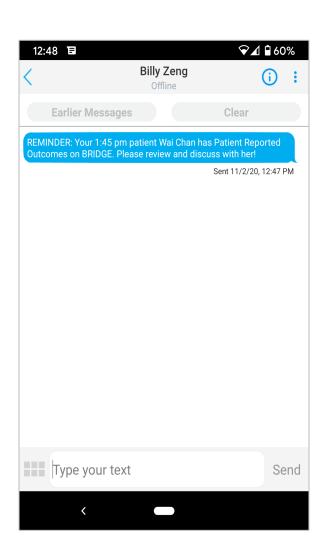
In between visits, if pat PRO excee clinical thre PCP gets a message.

e.g., Ms. Cl GAD-7 sco (threshold f is 10)

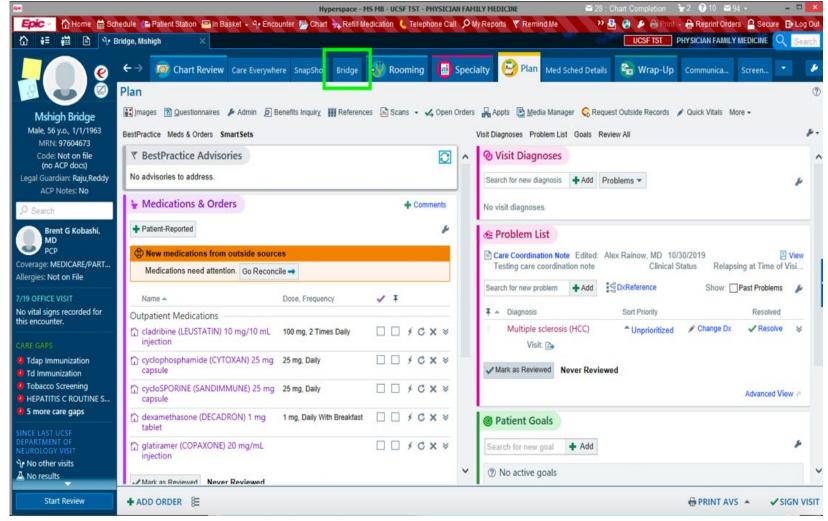


During Scheduled Visit





Day of visit: secure text reminder via Voalte



During visit: click on BRIDGE tab during in-person, telehealth, or telephone encounter

Reflections from mPROVE Project



Patient-reported Outcomes

- ► Multiple UCSF clinics and research projects interested in collecting PROs, as is health center
- ▶ Need both general PROs and condition-specific PROs
- ➤ To facilitate longitudinal PRO collection, PROs need to be useful to the patient *first and foremost:* clear purpose; salience; language, cultural, and health literacy concordance

Workflow integration

- ► Exploit FHIR APIs and SMART-on-FHIR protocols to automate and integrate
- Use pre-existing workflows where possible
- COVID times: minimize In Basket messages! and no tech or workflow burden on clinical staff

But we have to stop building one-off solutions!

Digital Monitoring for Virtual Care



- Patient-generated data (PGD) are a remote window into patient health states
 - patient-reported outcomes (PROs)
 - home medical devices (e.g., BP cuffs, glucometers), wearables (e.g., FitBit, AppleWatch), other sensors
- How to get from here to there?



1000 flowers blooming



Small individualized bouquets for diverse users

Pain Points (Health System Perspective)



Technical and Governance

- Multiple projects are (re)-building the same PGD ingestion & storage infrastructure with security, cost, and quality downsides
- Fragmentation impedes governance over PGD projects

Patient Trust

 Lack of unified view of patient-specific PGD data flows impedes data oversight and may undermine patient trust

Precision Medicine / Learning Health System

- Heterogeneity of data collection, formats, and patient consent impedes use of PGD for model building
- Duplication and heterogeneity of end-user systems impedes delivery of decision support to clinicians and patients

Digital Monitoring Using Only Epic/MyChart



Pros

- Med center has full control, lower security risks
- All clinical units use the same approach
- Remote data is stored in Epic for billing
- Clinicians can see remote and cliniccaptured data together
- Device agnostic: works for any BP cuff integrating with HealthKit or GoogleFit
- MyChart is a trusted "one-stop shop" for many patient EHR activities

Cons

- MyChart is not that user-friendly
- MyChart does not support characterbased languages like Chinese
- Forces Android patients to share data with Google (HealthKit data stays on the iPhone)
- How does digital health research fit in?
 - Restricted to using only Epic's decision support tools
 - Restricted to Epic's user interface
 - Restricted to commercial devices that integrate with HealthKit or GoogleFit
 - MyChart does not support patient-facing data-driven decision support

Towards Individualized Bouquets





1000 flowers blooming

Modular, standards-based PGD



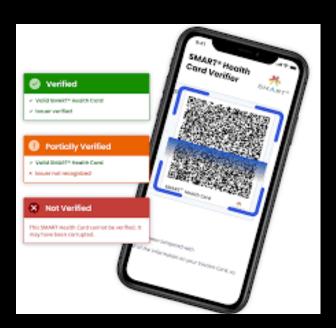
Small individualized bouquets for diverse users



Independent Nonprofit Public Trust

The Commons Project is a 501c3 non-profit public trust, established to build digital services that **put people first.** The Commons Project fills the void between tech companies, government agencies, and traditional non-profits to build and operate the digital services that constitute public infrastructure for the digital era.

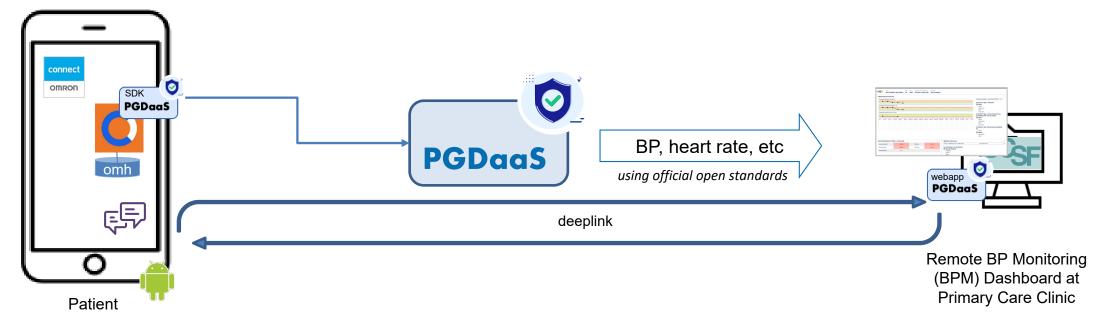




PGDaaS: A Public Utility







Use CommonHealth app to collect PGD under the CommonTrust Network

Standardized open public aggregator

PGD Client





Summary



- PROs for multiple chronic conditions need to be useful first and foremost for the patient
- PRO display and decision support can be integrated into workflow using SMART-on-FHIR
- PGD are a window into patient health states
 - ► To address multiple chronic conditions, PGD must be useful and usable *in individualized combinations* for each patient (i.e., individualized bouquets)
 - ➤ To be sustainable in the long run, health systems must be able to govern and manage PGD collection and usage while maintaining patient trust
- A public digital utility that serves PGD as standards-based data can anchor a modular, flexible, trustworthy PGD ecosystem

mPROVE/PGDaaS Team



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Transforming Healthcare Through Patient-Generated Health Data Integration

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Assistant Provost for Data Science and Informatics, Chief Research Information Officer Medical University of South Carolina

Overview



What are the practical issues with use of PGHD streams in ambulatory EHR systems?

- Initiate
- Configure
- Secure
- Analyze/Summarize
- Reintegrate, including workflows

Approaches To Integrate PGHD

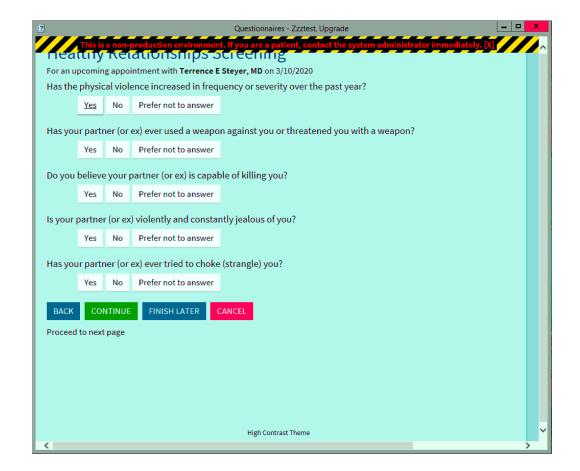


- EHR resources
 - ► Captive or "Kiosk" mode—secure, private, but logistically difficult
 - Tethered portal
- Smart-on-FHIR interaction with a gateway and a mobile app
- Deep Linkage plus gateway sets up 2-way communications with app or REDCap

Patient Data Entry in Captive Mode: Intimate Partner Violence Screening In Primary Care R18: HS025654



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			•	ce E Steyer, MD on 3/10/2020	
safety upon	/ in your re your respo	lations onses o	hip. Your answers o	le's lives and can impact health, we would like to ask you a few questions about n this self-report measure will be confidential and no one will take action based nout further speaking with you. Your doctor may follow-up with you about the ety.	
	cates a red				
Hav				oushed, shoved, or otherwise hurt by someone at home in the past year?	
	Yes	No	Prefer not to answ	ver	
*Do y	you feel s	afe in y	our current relatio	onship?	
	Yes	No	Not Applicable	Prefer not to answer	
*Is th	nere a par	tner fr	om a previous rela	tionship who is making you feel unsafe now?	
	Yes	No	Prefer not to answ	ver	
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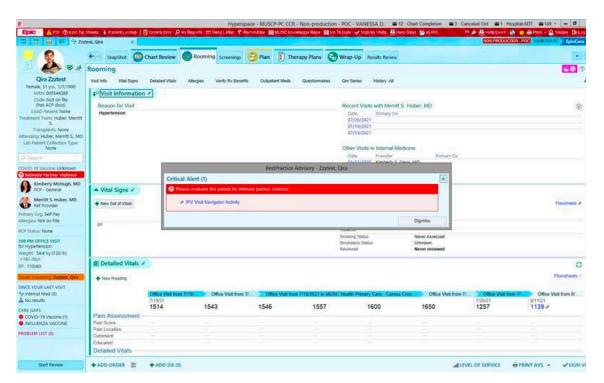


Registry tracks patient screening—BPA reminds provider to convert to captive mode and screen

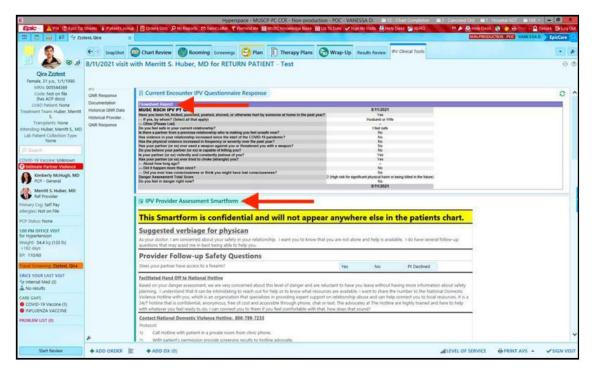
Provider Response: Assess IPV Risk



Alert



Confidential documentation



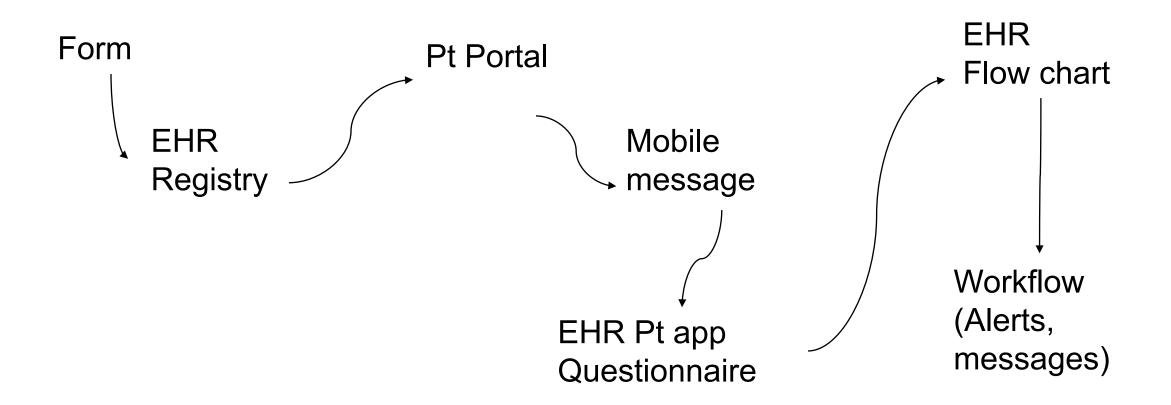
Clinic Compliance With IPV Screening



	I							
Period	2021-11-29 to 2021-12-13 🗾							
Visit Count	Questionnaire Status							
Department	Eligible/Not Screened	Screened	Total Eligible	Screened %	Positive	False positive	Positive for Research	
	15	13	28	46,43%				
	34	15	49	30.61%				
	71	. 23	94	24.47%				
	9	16	25	64.00%				
	9	25	34	73.53%				
	51		51	0.00%				
	27	8	35	22.86%				
	5	10	15	66.67%				
	22	7	29	24.14%				
	15	9	24	3 7.50%				
Total Eligible	258	126	384	32.81%	C	0	0	

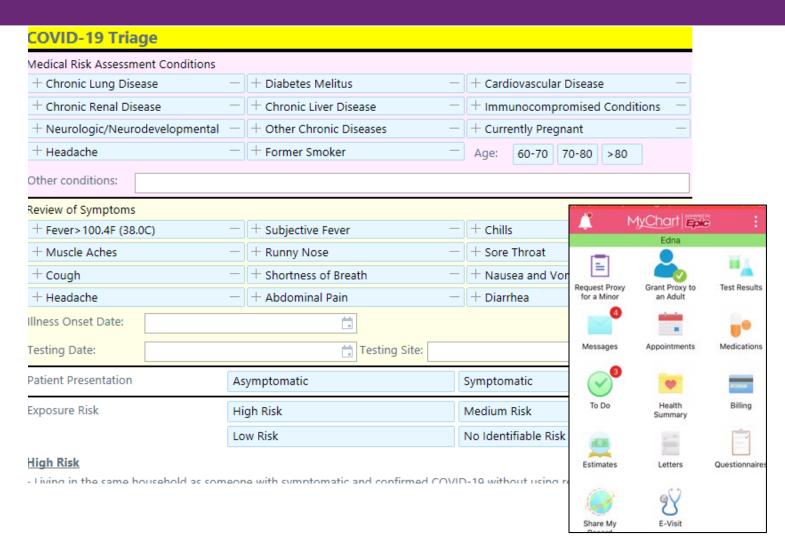
Tethered Example in Epic





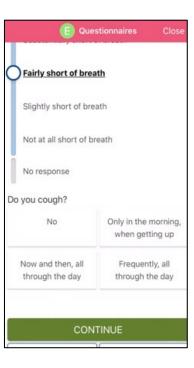
COVID-19 Example





MyChart App

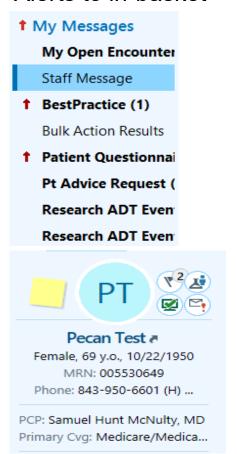




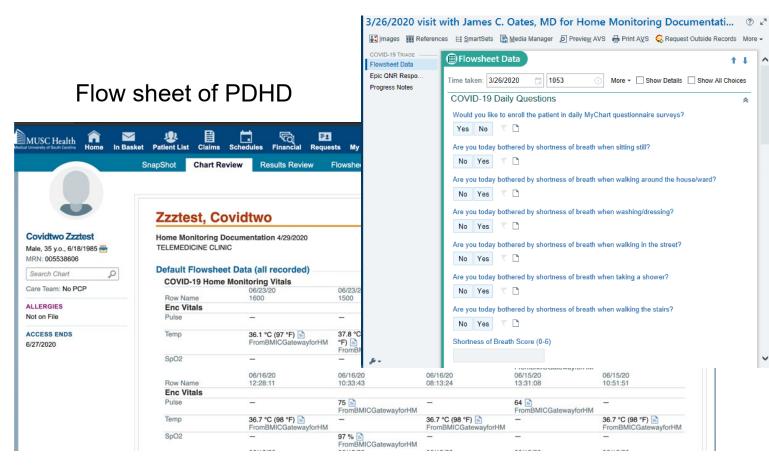
Provider Review of Data



Alerts to in-basket



Nurse encounter interface



Note being authored



Images used with Permission of Epic Systems

Care for COVID-19 Patients at Home at High Risk for Complications



Telemedicine Reports Volume 2.1, 2021 DOI: 10.1089/tmr.2021.0020 Accepted September 3, 2021 TMR-2021-0020-ver9-Ford_1P
Type: other
Telemedicine
Reports

Mary Ann Liebert, Inc. & publishers

SHORT REPORT

Open Access

Journal of the American Medical Informatics Asso

Not Home Alone:

Advance Access

Leveraging Telehealth and Informatics to Create a Lean Model for COVID-19 Patient Home Care

Research and Applications

▶ Dee Ford,¹ Emily Warr,² Cheryl Hamill,² Wenjun He,³ Ekatrina Pekar,⁴ Jillian Harvey,⁵,*,i Ragan DuBose-Morris,² Kimberly McGhee,³,6 Kathryn King,² and Leslie Lenert8

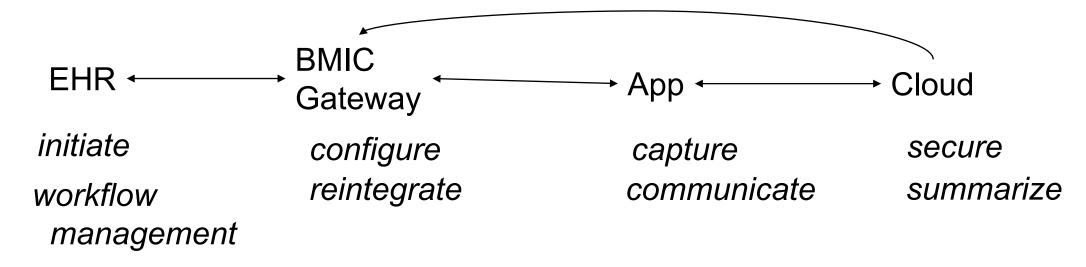
Leveraging health system telehealth and informatics infrastructure to create a continuum of services for COVID-19 screening, testing, and treatment

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Generalizing to Apps: Components

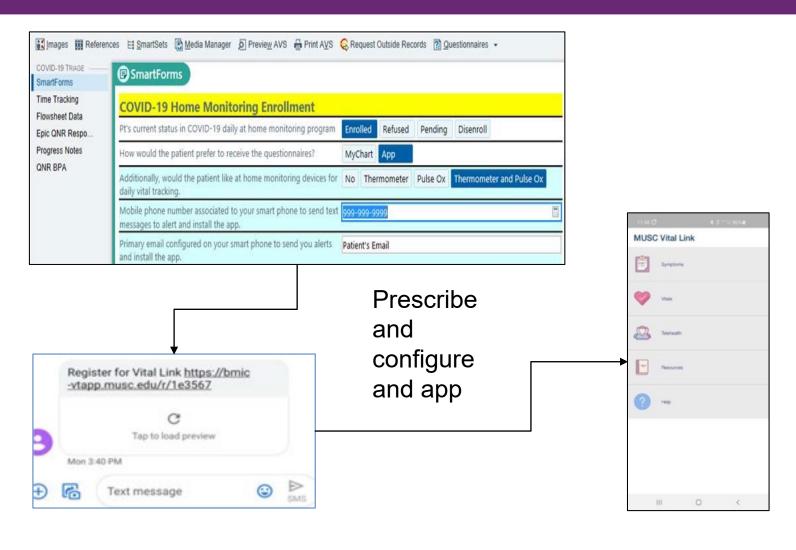


- EHR customization and workflow
- Standards-based gateway functionality (middleware)
- App-based functionality
- Cloud-based pre-processing



Deep Linkages for App Configuration





- (app downloaded)
- Text message with URL sent
- 3. Deep link opens app and redirects in app
- 4. Patient initiates configuration in app
- App receives encrypted linking identifier
- 6. App receives instruction for monitoring

What Is A Deep Linkage?



 Deep linkages are URLs that trigger an operating system level function to move a person browsing a website from the browser to view the same content (and maintain the same state) in the corresponding app.

website

web page with content

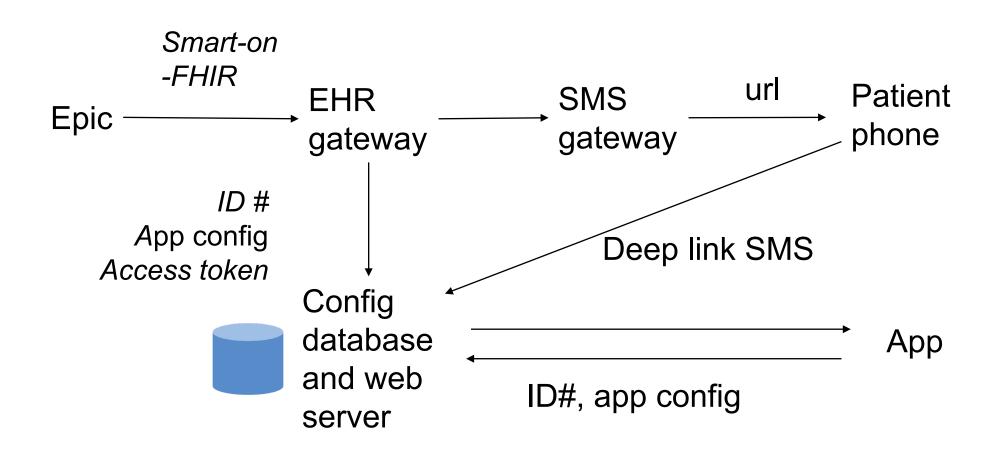
deep link

app in same state as website

We apply deep linkages to send information between EHR and an app (in this case a consent website) to configure the app

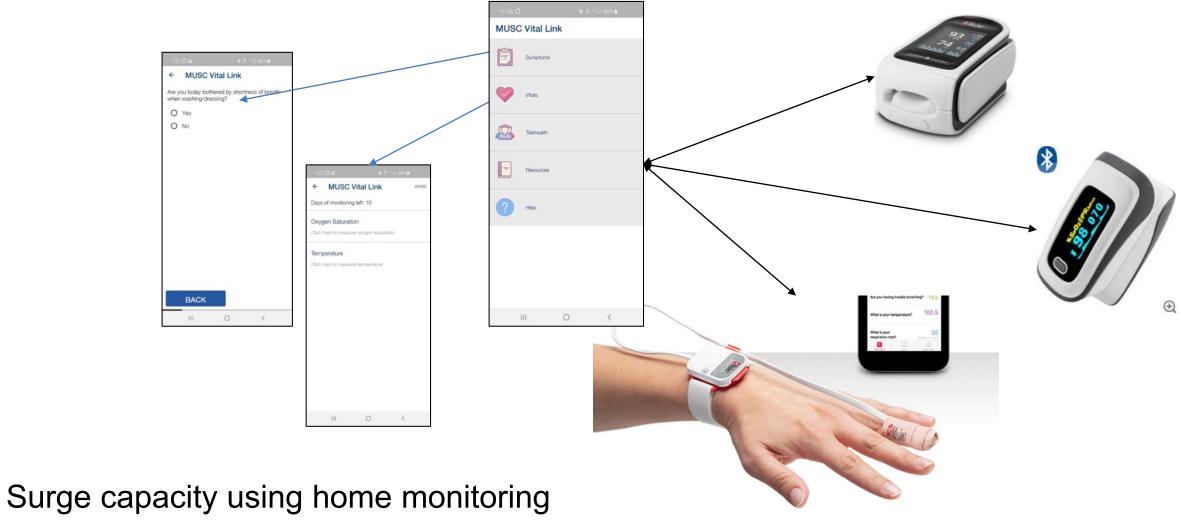
Initiation





App Configuration: Questionnaires and Devices



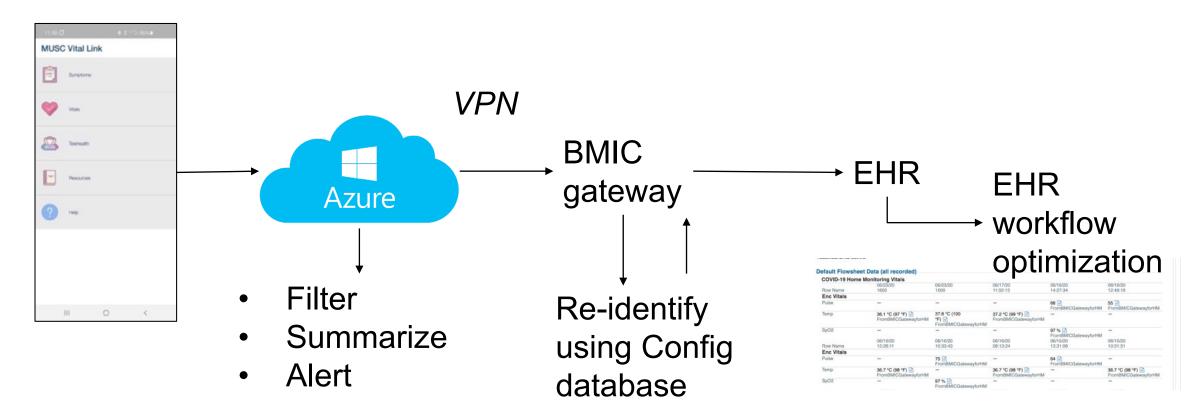


TATRC contract

Secure Reintegration of Data



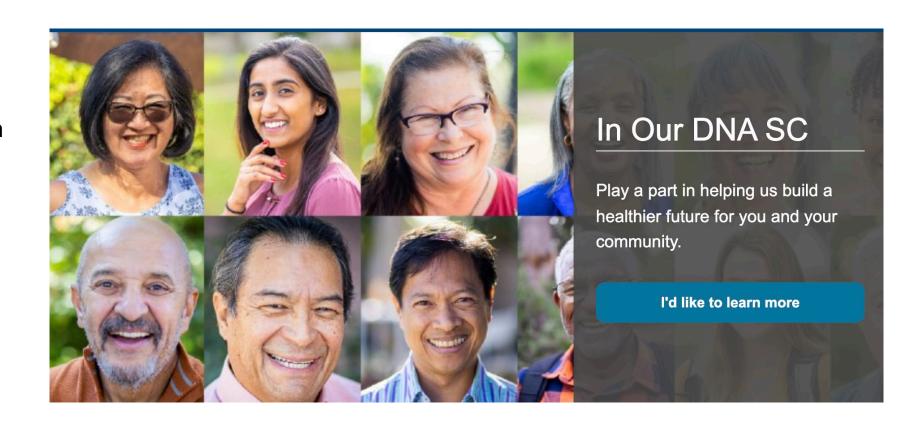
Avoiding direct connections from "unsupervised" devices to gateway middleware for security



In Our DNA SC Enrollment

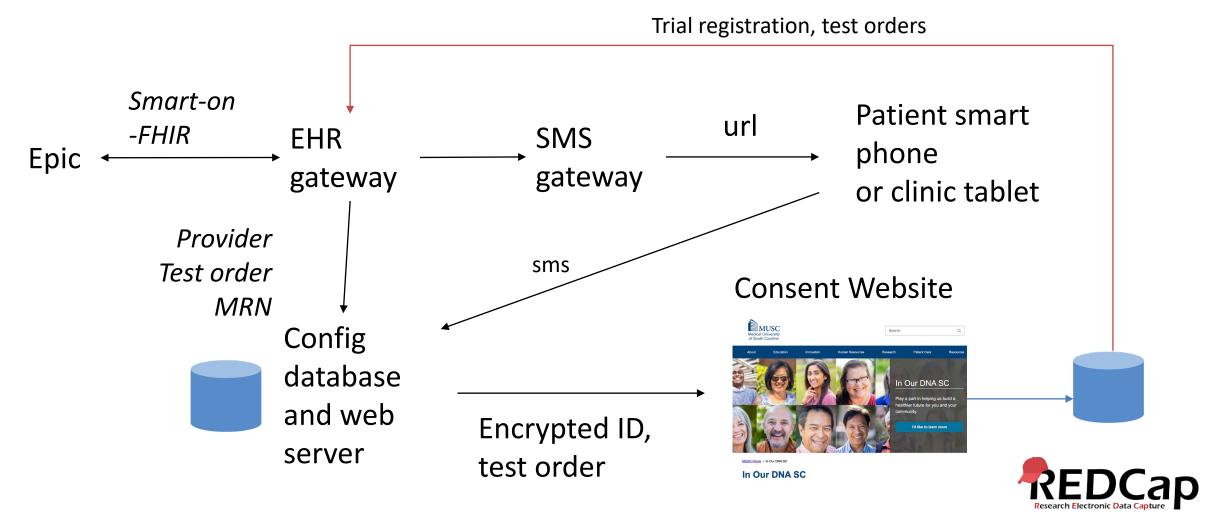


In Our DNA SC is a Precision Medicine Research initiative in collaboration with Helix. This initiative will recruit and sequence the DNA of 100,000 South Carolinians.



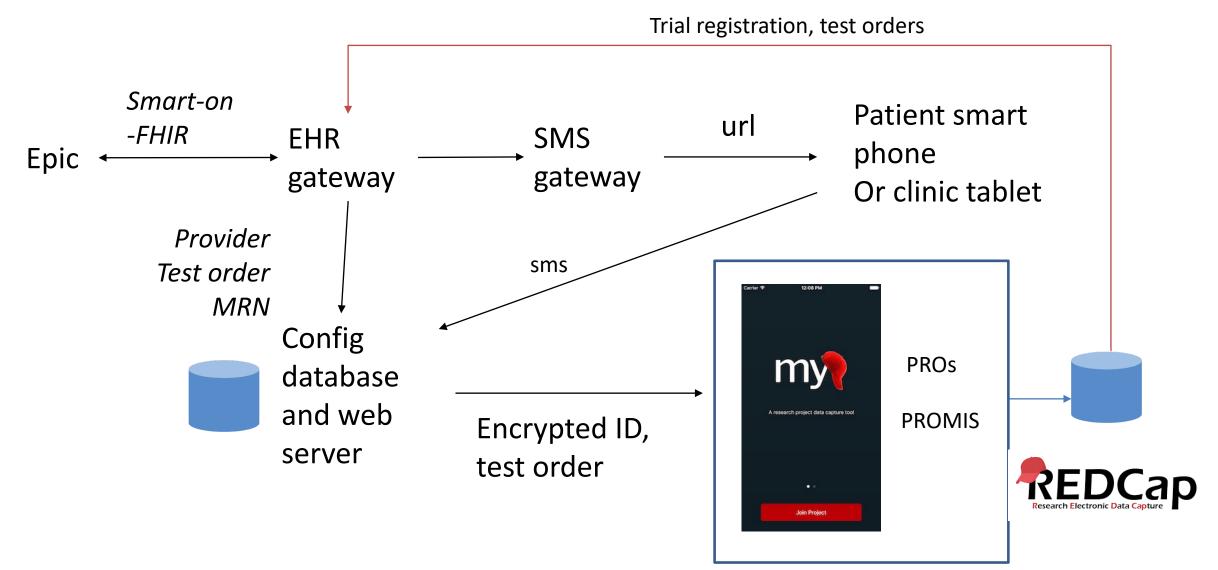
Deep Linkage to REDCap and Back to Epic





Deep Linkage to REDCap and Back to Epic





Summary



Tethered systems are practical and capable

- ► Capture mode (kiosk) good for confidential PGHD (IPV)
- Workflow integration is much easier with tethered systems

App integration requires some infrastructure

- Gateway for app connections (read, write back)
- Cloud filtering enhances security

SMS Deep Linkages add capability to apps

- Confidential record linkage with app
- App configuration
- Extends to REDCap and potentially other PRO platforms

Contact Information



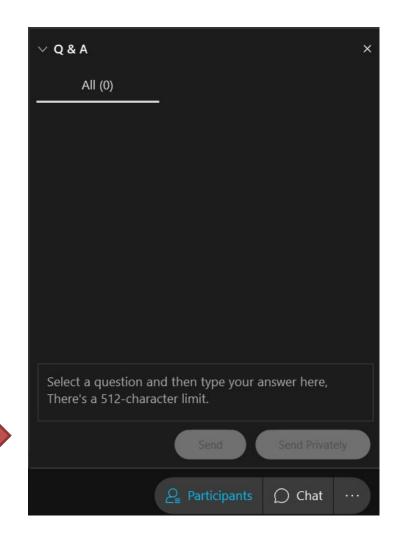
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